

Delaware Developmental Disabilities Council (DDC)
Adult Issues Committee
Minutes of Meeting, Friday, October 21, 2016
DDDS Fox Run, ~~2nd floor training room~~ Conference Room A
2540 Wrangle Hill Road, Bear, DE
And
Teleconference
302-526-5475
Conference ID 6940783#
9:30 AM to 12:00 PM

Members present at meeting location: **Terri Hancharick**, Committee Chair, Parent Advocate; **Karen Gallagher**, Self-Advocate, Committee Vice-Chair; **Carol Barnett**, Division of Services for Aging Adults and Persons with Physical Disabilities (DSAAPD); **HarrietAnn Litwin**, Division of Vocational Rehabilitation

Members Absent: **Alvin Emory**, Self-Advocate; **Bill Monaghan**, Advocate, Delaware People First; **Barbie Monaghan**, DDC Chair, Advocate, Delaware People First; **Vivian Turner**, Director-Collaborative Efforts to Reinforce Transition Success (CERTS); **Gary Mears**, Parent Advocate

Members Attending Via Teleconference: **Laura Strmel**, St. John's Community Services

Staff Present: **Kristin Cosden**, Social Services Administrator, Delaware Developmental Disabilities Council (DDC); **Pat Maichle**, Executive Director, DDC

Guests Present: **Katie Macklin**, Delaware Alzheimer's Association

I. Call to Order: After finding that the reserved meeting room was double-booked, the committee convened in Conference Room A. Staff at the Delaware Division of Developmental Disabilities Services apologized for the confusion and double-booking. The meeting was called to order at 9:46 AM. Chairperson Terri Hancharick noted that a quorum was present. Introductions were made around the room.

II. Approval of Minutes: The committee voted to approve the September 20, 2016 minutes as written.

III. Approval of Agenda: The committee voted to approve the agenda as written.

IV. -Chair's Report: Terri Hancharick shared that she recently traveled to Washington, DC to attend a summit focused on supported decision-making over the lifespan. Terri stated that there was a diverse representation of attendees, including parents/family members, self-advocates, lawyers and physicians. Terri shared that the Autistic Self-Advocacy Network (ASAN) is expected to publish a white paper on supported-decision making soon. Terri said that the summit was extremely informative and useful to her advocacy.

V. - Staff Report: Pat Maichle reported on the work she has been doing to help with the Delaware Developmental Disabilities Council's objective to address the high correlation between individuals with Down syndrome and developing early-onset Alzheimer's disease. Pat said that she has held meetings with Dr. Mary Stephens of Christiana Hospital as well as Katie Macklin of the Delaware Alzheimer's Association. Pat stated that these preliminary meetings have been enlightening, and that she looks forward to a continued partnership. Pat shared that she has another meeting scheduled for November to meet again with Dr. Stephens and Katie, as well as Dr. Ellison of the Swank Memory Center.

VI. Current Business

A. Discussion with Special Guest Katie Macklin of the Delaware Alzheimer's Association.

This discussion was planned in reaction to the Adult Issues Committee being assigned an objective within the new Delaware Developmental Disabilities Council Five Year State Plan dealing with the correlation between Down syndrome and Alzheimer's disease. Katie Macklin of the Delaware Alzheimer's Association agreed to attend the AI Committee meeting as a subject matter expert/community partner to help the AI Committee begin strategizing how to address this objective. Katie began by sharing information about the many resources that the Delaware Alzheimer's Association has to offer. These include a website, 24/7/365 toll free help line, numerous written resources and information about other community services for individuals with Alzheimer's and their families/caregivers.

Katie spoke about her colleague Mike Splain, who is now a consultant. Katie shared that Mr. Splain is presently at a conference in Scotland focusing on Alzheimer's and Intellectual Disability. Katie stated that other countries are a bit farther ahead in their examination of the co-existence of Down syndrome and Alzheimer's. Katie shared that here in the United States, 29 state plans on Alzheimer's (out of 50) mention the correlation between having Down syndrome and developing Alzheimer's as a policy priority.

In the US, some common themes have emerged around this topic, including the need for a comprehensive screening tool, a better trained care provider base equipped to assist individuals with DS/Alzheimer's, more research, increased support for caregivers, and more support for advance planning for families. Pat asked if any of the state plans address end-of-life; Katie stated that she is not aware of any Alzheimer's state plans in the U.S. which address end-of-life specifically.

Katie shared a resource from Scotland titled, "Jenny's Diary", which details the Alzheimer's journey of a young woman with a cognitive disability who has developed Alzheimer's. The diary is written from three perspectives; that of Jenny, her family/caregiver and her boyfriend. Each section is targeted to what the individual

reading would need. For caregivers, it talks about home and job modifications and shares how Jenny's thought process may change. For her boyfriend, it includes details about what to expect and how to be an ally and a comfort to Jenny. For Jenny, it includes some practical tips for keeping her schedule as close to "normal" as possible. Katie stated that Mr. Splain will likely have other resources to share from the conference in Scotland, but that he would not be at liberty to share those resources until after the conference has concluded.

As a result of the conversation, the following action items were suggested: Pat will invite Sara Weir of the National Down Syndrome Society to present to Council and will also ask if the NDSS has any resources about Alzheimer's and Down Syndrome; Kristin will add Katie Macklin to the AI Committee membership roster; Terri will ask George Tilson to attend the November or December AI Committee meeting.

- B. **Information Items from Committee Members:** Carol Barnett brought an idea to the AI Committee's attention. Carol suggested the development of a resource to assist individuals with disabilities find opportunities to engage in the community. She suggested this as a "Community Involvement Template". The idea is to have the template become a part of the Community of Practice work that is currently being done. Carol stated that she envisions the template being complimented by volunteers to spend time with and help guide individuals with disabilities who would like to become more active in their community.

VII.

There being no other new business, the meeting was adjourned at 11:14 AM.